



## caBIG Data Sharing and Intellectual Capital Working Group (DSIC WG)

### Survey on Data Sharing Restrictions

#### Respondent's Contact Information

Cancer Center:  
Division (e.g., tech transfer, industrial relations, etc.):  
Cancer Center Role in caBIG (developer, adopter):  
Contact Name:  
Contact E-Mail:  
Contact Title:  
Contact's Degree(s):

#### Survey Purpose

The National Cancer Institute (NCI)-designated Cancer Centers have agreed to partner with the NCI in the development of the Cancer Biomedical Informatics Grid (caBIG) (<<http://cabig.nci.nih.gov/>>). The caBIG pilot initiative seeks to integrate data from more than 50 cancer centers in ways that make it useful for clinical and basic researchers to consume of the vast array of genetic and clinical information. As a result, caBIG will offer Cancer Centers a library of tools and resources, from clinical trial management systems to tissue bank and pathology tools, all of which are built on common standards and are interoperable. Participation in caBIG is voluntary, and the data sets submitted and supported by caBIG will be openly accessible to the caBIG community. It is recognized that not all data can be shared because of agreements with industry partners; however, caBIG participants are encouraged to share as much data as possible.

The NCI structured the caBIG initiative to include the Data Sharing and Intellectual Capital (DSIC) Working Group of caBIG, which has among its chartered responsibilities the exploration of issues concerning data sharing and intellectual capital in the caBIG initiative. To the extent that an individual Cancer Center has entered, or will enter, into agreements with industry partners granting rights in genetic and clinical data, the Center may not be able to make such data available for the caBIG network. Therefore, the following survey is designed to develop a sense of each of the participating caBIG institutions' freedom to share its data. Specifically it is designed to answer the question of what restrictions may be placed on each institution's data as a result of collaborations with industry and academic institutions. For the sake of simplicity, this survey assumes that all privacy, confidentiality, HIPAA and/or IRB requirements have been met. Please answer to the best of your ability and add comments as appropriate. **All information obtained from this survey will be kept confidential and will only be distributed in de-identified, or aggregate, form.** Please submit your responses **thirty (30) days** following receipt of the survey. The DSIC Working Group recognizes that responding to the survey will require time on your part to search databases and prepare responses. Therefore, please know that your efforts are greatly appreciated.

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## EXISTING AGREEMENTS

The first set of questions is geared to a variety of agreements. To assist you in searching your document databases and/or other records, please consider the following types of agreements with industry or other academic institutions as you answer the questions:

- Agreements transferring specimens, etc. from cancer centers to industry or other academic institutions in exchange for services (e.g., hybridization and raw data output)
- Agreements transferring materials (e.g., drugs, compounds, reagents or research tools from industry or other academic institutions to cancer centers in exchange for data generated from the use of the provider's material tissues, human or animal)
- Clinical trial agreements in which industry provides investigational agents and funding to cancer centers in exchange for resulting clinical trial data
- Sponsored research agreements in which industry provides funding for research carried out in a cancer center researcher's laboratory
- Research collaboration agreements with industry partners or other academic institutions in which some assistance is provided to cancer center investigators in the form of research effort, materials, data, funding or some combination thereof
- Agreements with industry or other academic institutions providing access to proprietary software, algorithms, databases or datasets for cancer center researchers

**If you respond affirmatively to a particular question, please estimate the number of applicable agreements relative to the total number of industry agreements as may be appropriate.**

1. Does your institution enter into relationships with industry or other academic institutions in which your institution's patient tissues and/or related data of any kind is exchanged?

No \_\_\_\_\_

Yes \_\_\_\_\_

2. If "Yes" to 1, do your agreements with industry or other academic institutions place any restrictions on sharing your institution's own data?

No \_\_\_\_\_

Yes \_\_\_\_\_

If Yes, please explain:

3. Do your agreements with industry or other academic institutions provide for your institution to receive data that is developed by industry or academic partners?

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No \_\_\_\_\_

Yes \_\_\_\_\_

4. If "Yes" to 3, do industry or other academic institutions have sole and/or exclusive access to the data for some period of time before they are required to provide data back to your institution?

No \_\_\_\_\_

Yes \_\_\_\_\_

5. If "Yes" to 4, are there any restrictions on your institution's use of the data once you have received it?

\_\_\_\_ Internal research use only (i.e., within your institution)

\_\_\_\_ Internal research use only by the study PI

\_\_\_\_ Other (please explain: \_\_\_\_\_)

6. Are there any restrictions to sharing industry-developed data generated from your institution's materials with third parties?

No \_\_\_\_\_

Yes \_\_\_\_\_

7. If "Yes" to 6, please specify persons permitted access:

\_\_\_\_ Other academic researchers

\_\_\_\_ Other industry partners of your institution

\_\_\_\_ National research databases such as caBIG

\_\_\_\_ Other (please explain: \_\_\_\_\_)

8. Does your institution enter into agreements with industry or other academic institutions in which restrictions are placed on the use of data generated from the use of your institution's materials and developed at your institution for the benefit of third parties?

No \_\_\_\_\_

Yes \_\_\_\_\_

9. If "Yes" to 8, please specify persons permitted access:

\_\_\_\_ Other academic researchers

\_\_\_\_ Other industry partners of your institution

\_\_\_\_ National research databases such as caBIG

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\_\_\_\_ Other (please explain \_\_\_\_\_)

## **INSTITUTIONAL POLICIES ON DATA SHARING**

The following questions are directed toward your institution's policies that affect the ability of your investigators to share data. Explanatory comments will be much appreciated.

10. Is your institution willing to freely share data generated from the use of materials developed at your institution that is not presently encumbered by restrictions imposed by industry partners?

No \_\_\_\_\_

Yes \_\_\_\_\_

If No, why not?

11. Is your institution willing to share data generated from the use of human tissues, specimens or related materials on which published papers are based?

No \_\_\_\_\_

Yes \_\_\_\_\_

12. If "No" to 11, please explain the reasons:

\_\_\_\_\_

13. Please explain the steps, beyond patient consent, privacy and IRB issues, that your institution plans to take to ensure that all data shared with caBIG can be shared:

\_\_\_\_\_

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